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Innovative and Community-Guided Evaluation and Dissemination of a Prostate Cancer Education Program for African-American Men and Women

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Abstract

African Americans (AA) are more likely to develop and die from cancer than any other racial or ethnic group. The aims of this research were to: (1) evaluate current education materials being implemented in a community-based prostate cancer education program for AA communities; (2) refine materials based on findings from Aim 1; (3) share updated materials with participants from Aim 1 for additional improvements; and (4) disseminate and evaluate the improved education program through a statewide videoconference with AA men and women. AA individuals evaluated the current education program through a mail survey (n=32) and community forum (n=38). Participants reported that the existing prostate cancer education program content could be understood by lay persons, but recommendations for improvement were identified. They included: defining unknown and/or scientific terminology, increasing readability by increasing font size and enlarging images, and including more recent and relevant statistics. Following refinement of the education materials based on survey and forum feedback, a statewide videoconference was implemented. Following the videoconference, participants (25 men; 3 women) reported that they would encourage others to learn more about prostate cancer, talk to their doctor about whether or not to get screened for prostate cancer, and would recommend the conference to others. There is great potential for using this type of iterative approach to education program development with community and clinical partners for others conducting similar work.

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Keywords

prostate cancer; African American; dissemination; cancer communication; videoconference; community-engaged research

Introduction

African Americans (AA) are more likely to develop and die from cancer than any other racial or ethnic group [1, 2]. Prostate cancer is the most commonly diagnosed cancer among men in South Carolina, especially among AA men [1, 3]. Prostate cancer is a salient issue in the AA community in South Carolina following recent scientific debates over the nature of evidence for or against prostate-specific antigen (PSA) testing, active surveillance, and treatment. Incidence rates in AA men in South Carolina are among the highest in the world (80% higher than in European-American men, who are at the U.S. average). AA men in South Carolina also experience the highest mortality from prostate cancer in the U.S. [1, 3].

Two large scale trials show varying results of the impact of prostate cancer screening on mortality and show evidence that the PSA test may lead to over-detection of slow growing, less harmful cancers; thereby leading to over-treatment of patients and poor quality of life [4,5]. Informed decision making (IDM) is an approach that is supported by the American Cancer Society to educate men about the prostate health and prostate cancer, given that scientific data is lacking or inadequate to promote universal screening for all men [6]. Participation in education programs about cancer, prostate health, prostate cancer, and medical research can help AA men make more informed decisions about their health and screening by having more knowledge about screening and treatment options.

Prevention programs that are tailored to AA communities have been used to reduce health disparities, including cancer health disparities. Incorporating culturally appropriate and targeted messages and images [7-10], conducting faith-based initiatives [11, 12], and delivering educational programs in non-traditional venues such as barber shops [13] and beauty salons [14, 15] have been commonly used. Engaging partners and stakeholders in the planning, implementation, and evaluation of health and cancer education programs is critical for improving the health of our communities and for encouraging community engagement, empowerment, and capacity building [16-18]. Thus, we developed a prostate cancer IDM education program for AA families in collaboration with community and clinical partners.

This National Cancer Institute (NCI)-funded pilot program was delivered within an AA community from 2011-2014 and was in response to the U54 Request for Applications (RFA-CA-09-032) for Community Networks Program Centers to propose a research program of innovative and evidence-based clinical research adhering to the principles of community-based participatory research (CBPR) [8, 9, 19, 20] Additional requirements for the pilot program included: collaborations with other NCI-sponsored clinical trials, collaborations with other NCI-sponsored resources/programs [e.g., the NCI Community Clinical Oncology Program (CCOP), the NCI Community Cancer Centers Program (NCCCP)], and promoting the role of racial/ethnic and other underserved populations in research [8]. In keeping with CBPR principles, a community advisory panel of AA men and women was established at the

beginning of the program to help guide all recruitment and project implementation and evaluation activities [8, 21]. The original program was developed based on input from 81 focus group participants during a formative research phase [8, 9, 19, 20]. Education topics include “Overcoming barriers to discussing cancer” and “Prostate cancer screening guidelines: Should I get screened for prostate cancer?”. When discussing prostate cancer screening guidelines and whether a man should be screened for prostate cancer, we also provided information on what men should discuss with their doctors and incorporated role-playing activities on how to make informed decisions regarding prostate cancer screening and/or treatment. Our education program has been one of very few initiatives to involve AA female family members in prostate cancer education.

While other programs have included women in formative work to assess their perceptions and knowledge about prostate cancer, [22, 23] this program is one of the first to include women in the education program along with men. The goal of this continued collaboration was to engage in a systematic approach to evaluating, refining, and more widely disseminating the existing prostate cancer education program for AA men and women in an effort to increase their understanding of the risks, benefits, and uncertainties of prostate cancer screening, treatment, and participation in research. The format of the existing education program included presentations (Microsoft PowerPoint™) and program materials (e.g., printed recruitment flyers, postcards, information sheets). The refined prostate cancer education program includes updated content formatted for more innovative and widespread dissemination via videoconference broadcasting to ensure that AA men and women are receiving plain language, culturally appropriate, and targeted prostate cancer information that will allow men to make informed decisions about screening, treatment, and participation in cancer research. Video-based teleconferencing is considered a an effective method for health promotion initiatives and interventions including those for smoking cessation [23], stroke management [24], breastfeeding support [25], and cancer education [26]. Additionally, video-based teleconferencing can be especially advantageous to rural communities that would not otherwise have easy access to relevant and timely health information [26]. The refined program was delivered in person at one central location in the state and the videoconference from the central location was broadcasted at two additional locations across the state with the assistance of additional community partners.

Methods

In an effort to refine and tailor the current prostate cancer education program to ensure that AA men and women are educated about prostate health, prostate cancer, and clinical research, the specific aims of this initiative were to: (1) evaluate current education materials being implemented in a community-based prostate cancer education program; (2) refine materials based on findings from Aim 1; (3) share updated materials with participants from Aim 1 for additional improvements; and (4) disseminate and evaluate the improved education program through a statewide videoconference with AA men and women.

To achieve aim 1, 32 AA men (n=21) and women (n=11) who participated previously in an offering of the community-based education program were mailed copies of the PowerPoint™ presentation slides and program materials along with a survey designed for

participants to review the education program. The survey included both quantitative and qualitative elements (25 total questions; 13 demographic questions, 9 open-ended questions, and 3 closed-ended questions). Demographic questions included: (1) What year were you born?, (2) What is your current marital status?, and (3) What was your household income in 2010? Open-ended questions included: (1) How can we improve the information provided in the education program? and (2) How can we improve the text on each slide so it can be read by the average person? Close-ended questions included: (1) Overall, do you feel that information provided in the education program can be understood by the average person?; (2) Overall, do you feel that the text on each slide is easy to read?; and (3) Overall, do you feel that the order of the slides is appropriate (i.e., has a natural flow)? This survey was not validated, but was developed based on health literacy and health communication principles [27]. Data from these surveys were compiled into an Excel file and used to achieve aim 2. During the refinement process, the project team, with the expertise of a graphic designer, created updated mock-up materials based on feedback from participants.

To achieve aim 3, a second round of evaluation was completed with 38 men and women (32 individuals from aim 1 and family members were in attendance). During this phase of the evaluation, participants from aim 1 were invited to an in-person community forum to provide additional feedback on the updated education program materials. Demographic information was not collected during this stage of the data collection process. Finally, based on forum feedback, the materials were further refined and pilot-tested through a statewide videoconference delivered to 28 men and women across the state at three broadcast sites. Each broadcast site was in a different region of the state. Three of the four regions of the state were represented because of relationships with community partners in these regions. The videoconference was advertised through flyers, listservs, and word-of-mouth by community and clinical partners. A pre-survey (33 total questions; 9 demographic questions, 3 open-ended questions and 21 closed-ended questions) and post- survey (39 total questions; 1 open-ended questions and 38 closed-ended questions) was administered to all videoconference participants to evaluate the impact of the webinar on participant knowledge, attitudes and/or beliefs relative to prostate cancer and research decision making and overall satisfaction with the content, format, and speakers. This survey was not validated, but was developed based on information from ClinicalTrials.gov's “Understanding Clinical Trials” article [28] and information gained from community members during the initial pilot research program [8, 9, 19, 20].

Analysis

The quantitative results from the prostate cancer education survey used in aim 1 were assessed using nonparametric frequencies and percentages. The statewide videoconference was assessed using a pre- and post-test measure. Non-parametric statistical tests (e.g., Wilcoxon rank sum test) and rates (e.g., frequencies / percentages) were used to examine videoconference survey results. Due to the small sample for the webinar (n=28), significance, at the traditional p value of .05 was not achieved for most items, but results demonstrating the greatest changes from pre- to post-test are discussed. Qualitative responses from the prostate cancer education survey and the videoconference pre/post-test measure were transcribed, compiled into a Word document, and examined for common

themes. The overall outcomes examined were feedback on program refinement, program satisfaction following program refinement, and participants knowledge, attitudes, and or/ beliefs relative to prostate cancer IDM and research decision making.

Results

Prostate Cancer Education Program Review – Initial Survey Results (Aim 1)

Quantitative Results—Thirty two AA males (n=21) and females (n=11) with an average age of 48.0 ± 17.4 completed the survey. Over half (53%) were single/never married while 32% were married. Most (76%) participants made below $29,000 in household income annually with many (35%) making less than $10,000 per year. Most participants were employed (50%) or retired (22%) and had above a high school education (88%). In addition, 70% had access to either private or public health insurance. See Table 1 for additional participant demographics.

Almost 85% felt that the existing prostate cancer education content could be understood by a lay person. Seventy percent also reported that the text on each slide was easy to read, but almost all of the remaining respondents reported that they were unsure. With regard to the format of the organization of the presentation, the majority of respondents (87%) reported that the presentation had a natural flow.

Qualitative Results—Participants were asked a series of open-ended questions regarding the content, format, and cultural appropriateness of the existing prostate cancer education program. When asked, “How can we improve the information provided in the education program so that it can be understood by the average person?,” participants generally mentioned clarifying some of the information, defining unknown terms, and using plain language. Specifically participants wrote, “what is selenium besides a mineral, not clear, should be explained/defined,” and “explain [PSA] exam process, what is the procedure”. When asked, “How can we improve the text on each slide to be read by the average person?” participants stated this could be accomplished by enlarging the print, adding pictures, and including more recent information. Specifically participants wrote, “slide #6, small print and wordy”, more up to date information - it's 2014”, and “text could be larger”. We also wanted to understand if the content of the presentation would be beneficial to both AA men and women wanting to learn more about the prostate, prostate health, and prostate cancer. Participants were asked about what types of information may have been missing from the education program. Topics for which participants requested additional information included: “more about screening”, “explain the exam process”, “more information on results of waiting vs. treatment, and “information on resources”. Finally, we wanted to know if participants thought that a man would have enough information (after completing this education program) to make an informed decision about prostate cancer screening. Most participants felt that the information was appropriate. For example, participants reported, “Yes, there is enough information to get an understanding of what prostate cancer is,” “Yes, it is good information”, and “I can make an informed decision from this information.” Overall, the qualitative results showed that participants thought the program was valuable and believed that AA men would be able to make an informed decision about prostate

cancer screening after receiving the education, however, they also made recommendations for updates.

Education Program Refinement (Aims 2 and 3)

As reported earlier participants expressed that the prostate cancer education program was valuable, provided useful information, and would help men make informed decisions about prostate cancer screening, but they also provided a great deal of feedback on ways in which the program could be improved. Participants requested that (1) photographs have more color and that diagrams are incorporated into the PowerPoint™ presentation, (2) technical terms are defined more clearly, (3) slides include less text, and (4) additional information is added about prostate cancer treatment. To address these issues, researchers worked with two expert consults knowledgeable in prostate cancer research and a graphic designer to improve not only the content, but the layout, design, and flow of the education program. The expert consults added additional information about the various types of treatment, and more clearly defined medical terms. The graphic designer modified the design and flow of the slides. Originally the slides only had a white background with low quality photos and graphics and a generic logo. The graphic designer changed the background to light blue, the color used to symbolize prostate cancer, and developed a personalized logo. The graphic designer with the help of the expert consultants also changed the flow and lengthiness of the slides. Some slides were combined for ease of flow, some slides were cut entirely, the font size was enlarged across all slides, and higher quality images and graphics were added. Once all of these updates were made, the education program was pilot-tested with participants in a community forum where they provided additional feedback. Suggestions from the forum included fixing typographical errors, reordering some slides, and providing more recent mortality and incidence data. The final version of the refined prostate cancer education program (based on the initial survey and community forum) was presented during the statewide videoconference. Findings from the statewide videoconference are presented below.

Statewide Videoconference Feedback- Pre/Post Survey Results (Aim 4)

Quantitative Results—The purpose of the prostate health video conference pre-and post-test was twofold. First, we wanted to measure any changes in knowledge about prostate cancer and prostate cancer screening and participants' health and cancer-related decision making. Second, we wanted to understand the utility of using a videoconference format to educate men and women about prostate health and prostate cancer. Twenty-eight AA individuals (25 men and 3 women) with an average age of 63.1± 8.8 completed the survey. More than 75% of the participants were married. Half of participants (50%) were retired and had above a high school education (79%). See Table 1 for additional participant demographics.

The prostate health videoconference was developed to educate men and women about prostate health, prostate cancer, and informed decision making with regards to prostate cancer screening. There were no significant changes in how people responded to any single knowledge item, however, there was a general increase in knowledge from pre- to post-test. The largest increases were on items that addressed prostate cancer diagnosis (i.e., "A

prostate biopsy is the only way to truly diagnose prostate cancer") and risk factors for prostate cancer (i.e., "Men who eat greater amounts of certain red meats are at a higher risk of developing prostate cancer.") The prostate cancer education program was designed to educate AA men and women about prostate cancer screening in particular and also explain the importance of making informed decisions about screening and with that message, the education program explains that not all men need to be screened and that not all experts recommend routine screening for all men. Although these messages were conveyed, a majority of participants still thought at both pre- (71.4%) and post-test (64.3%) that all experts agreed that all men should get screened for prostate cancer. Additionally most participants reported incorrectly at both pre- (89.3%) and post-test (92.9%) that all healthy men should be screened annually for prostate cancer. See Table 2 for data on all knowledge items.

We also wanted to understand how well received the videoconference format was for participants and the utility of using this type of dissemination strategy to educate AA men and women about prostate cancer. Most of the men and women who participated in the videoconference felt that the organization of the program was excellent (85.7%); the subject matter was relevant (89.3%); and the videoconference format was appropriate (85.7%). Additionally, after attending the videoconference, participants reported that they would encourage others to learn more about prostate cancer (67.9%) and encourage others to talk to their doctor about whether or not to get screened for prostate cancer (71.4%). When participants were asked how they would like to engage with their doctor in making a decision on whether or not to get screened for prostate cancer, the most preferred way to make a screening decision was for the individual to make the final decision after seriously considering their doctor's opinion (pre-57.1%, post-39.3%). Fewer preferred to make the decision solely on their own (pre-10.7%, post-7.1%), and some preferred for the doctor to make the final decision after he/she seriously considered their opinion (pre-17.9%, post-25.0%). Finally 100% of participants would recommend the prostate cancer education program via videoconference to others.

Qualitative Results—The videoconference used to deliver the prostate cancer education program was broadcasted at 3 locations across the state and hosted by community and clinical partners. Recruitment was conducted across the state and as a result we wanted to understand how people learned about the videoconference. Overall, most people heard about the videoconference through one of our community partners (academic, community, and clinical) or word-of-mouth. The grassroots marketing strategies utilized by community partners were very successful in creating engagement both prior to and following the program. Interactions between the participants and speakers were dynamic and highly interactive because of the use of videoconferencing. Sites were addressed by their name/location and the small group environments keep the tone of the program conversational. When asked for the main reason for attending the videoconference, participants most often reported wanting to learn more about prostate cancer, how to make an educated and informed decision about screening and treatment, and increase their general awareness about the prostate and prostate cancer. When asked what we could do to improve the videoconference program, very few suggestions were given. The most notable

recommendation was to make the broadcast clearer both in sound and picture quality Overall, based on both the quantitative and qualitative results, participants enjoyed the program and would recommend the program to others.

Discussion

The specific aims of this research were to: (1) evaluate current education materials being implemented in a community-based prostate cancer education program; (2) refine materials based on findings from Aim 1; (3) share updated materials with participants from Aim 1 for additional improvements; and (4) disseminate and evaluate the improved education program through a statewide videoconference with AA men and women. While other programs have included women in formative work to assess their perceptions and knowledge about prostate cancer, this program is one of the first to include women in the education program along with men.

Our findings revealed that the existing prostate cancer education program content could be understood by lay persons, but changes to improve the education program were also identified by program participants. Those changes included defining unknown and/or scientific terminology, increasing readability by increasing font size and enlarging images, and including more recent statistics. Following refinement of the education program content based on the above feedback and after receiving additional feedback from the community forum, the statewide videoconference was held. Following the videoconference, participants reported that they would encourage others to learn more about prostate cancer, talk to their doctor about whether or not to get screened for prostate cancer, and would recommend that conference to others.

The importance of this work lends from the iterative, community-engaged approach to developing and refining cancer education programs in collaboration with relevant and credible clinical and community partners that are most trusted by the intended community. Engaging partners and potential stakeholders in cancer education programs is essential for improving community health and encouraging and supporting sustainability of such programming [16-18]. The statewide videoconference was recorded and the online link that has been shared with communities via the state cancer alliance can be used by other researchers, partners, funders, and stakeholders to continue to educate AA men and women and cancer, prostate cancer, and general prostate health.

This mixed-methods study has limitations. The sample consisted of a small number of AAs across the state and an especially small number of women even though the program is intended for both AA men and women. While the results showed that participants increased their knowledge about the prostate and prostate cancer, few to no results were statistically significant. Additionally, the results may not be generalizable to other participants outside of the state of South Carolina. Despite these limitations, this pilot study provided valuable information that can contribute to future cancer education program development and sustainable clinical-academic-community partnerships. Furthermore, including both men and women in our study allowed for a broader family approach to education about prostate

cancer screening and treatment, particularly if women are the overall health advocates for their families [9].

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Table 1

Participant Demographics

	Prostate Cancer Education Survey (n=32)	Statewide Videoconference Survey (n=28)
AGE (years)	48.0 ± 17.4	63.1 ± 8.8
GENDER	**Frequency(Percent)***	**Frequency(Percent)***
Male	21 (65.6%)	25 (89.3%)
Female	11 (34.4%)	3 (10.7%)
MARITAL STATUS		
Single	17 (53.1%)	0 (0%)
Married	10 (31.3%)	22 (78.6%)
Separated	0 (0%)	0 (0%)
Divorced	3 (9.4%)	3 (10.7%)
Widowed	2 (6.3%)	1 (3.6)
Other	0 (0%)	0 (0%)
EMPLOYMENT STATUS		
Employed	16 (50.1%)	8 (28.6%)
Self Employed	-	1 (3.6%)
Unemployed	3 (9.4%)	1 (3.6%)
Retired	7 (21.7%)	14 (50.0%)
Unable to Work	3 (9.4%)	2 (7.1%)
Other/Missing	3 (9.4%)	-
RACE		
White	-	4 (14.3%)
Black	32 (100%)	24 (85.7%)
HIGHEST EDUCATION LEVEL		
Less than High School	4 (12.5%)	1 (3.6%)
High School/GED	9 (28.1%)	5 (17.9%)
Some college	13 (40.6%)	10 (35.7%)
College or Higher	6 (18.8%)	12 (42.9%)

*Totals in each section vary due to missing responses

Table 2

Pre/Post Statewide Videoconference Survey Results

Prostate Cancer Knowledge*		
	All Participants n=28	
Item	**Pre-Test**	**Post-Test**
Both men and women can develop prostate cancer. (NO)**	89.3%	96.4%
The prostate is located below the bladder and in front of the rectum. (YES)	82.1%	89.3%
A man can have prostate cancer without having symptoms. (YES)	78.6%	92.9%
All experts agree that men should get screened (or tested) for prostate cancer. (NO)	28.6%	35.7%
Men should know the risks and benefits of prostate cancer testing before getting screened for prostate cancer. (YES)	85.7%	89.3%
A high PSA (prostate specific antigen) test result can suggest that a man has prostate cancer when he really does not. (YES)	78.6%	82.1%
The older a man is, the greater his risk for getting prostate cancer. (YES)	75.0%	75.0%
Prostate cancer affects only older men. (NO)	85.7%	82.1%
A prostate biopsy is the only way to truly diagnose prostate cancer. (YES)	53.6%	75.0%
Men who eat greater amounts of certain red meats are at a higher risk of developing prostate cancer. (YES)	64.3%	89.3%
A man with a father, brother, or son who has had prostate cancer is two to three times more likely to develop the disease. (YES)	67.9%	85.7%
Healthy men should be screened annually for prostate cancer. (NO)	10.7%	7.1%
Prostate cancer screenings are not 100% accurate. (YES)	25.0%	78.6%

* No changes were statistically significant at $P<.05$.

** The answer provided in parenthesis following the item is the correct response. The percentage of those participants that answered the item correctly is reflected in the pre-test and post-test columns.